

PARAPLEGIA NEWS MAY 2025

# PN

**Becoming A “Mama Bear”**

Being a mother with SCI/D

**The Next Big Breakthrough?**

PVA awards 2025 research grants

# Austin Agenda

PVA convention heads to the heart of Texas







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Courtesy of Austin Public Library

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*by the Paralyzed Veterans of America  
Research & Education Department*

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*by Lisa Van Loo*

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*by Andy Nemann*

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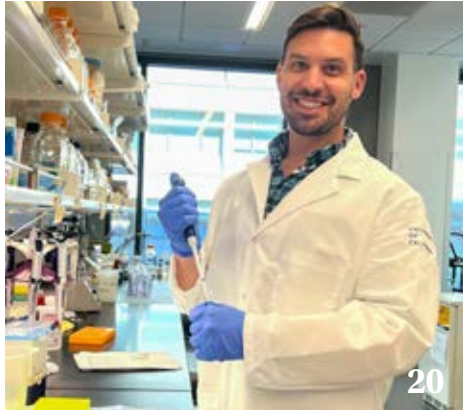
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"Controlling fingers is a stepping  
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— Nishal Shah, PhD

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Now in its 79th 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](http://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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# MAY Editor's DESK

**Nobel Prize-winning author** and poet Rudyard Kipling once said, "God could not be everywhere, and therefore he made mothers."

For as good as that quote is, it probably doesn't come close to covering all that mothers do. From months of pregnancy to years raising a child, that old adage of "a mother's work is never done" is easy to understand. Of course, this is the month we celebrate moms, and we thought the May issue would be a good time to take a look at being a mom with spinal cord injury and disease (SCI/D). *Motherhood Moments* on page 34 introduces you to a few moms with SCI/D and their challenges and joys.

May is also the month for the Paralyzed Veterans of America (PVA) Annual Convention. This year, PVA will be in Austin, Texas, for business, camaraderie, tasty barbecue and more. If you're going to the convention, *Deep In The Heart of Texas* on page 26 will give you a few ideas on local attractions, places to eat and even information about the city's famed bats (yes, bats), featured on this month's cover.

Also in this month's issue is an article detailing some of the important work PVA does to help everyone with disabilities. *Granting Research* on page 20 is a look at research grants awarded by the PVA Research Foundation. These grants help fund important studies that deal with everything from exo gloves to cognitive testing.

We hope you enjoy those articles and all the other great content in this month's issue. Happy Mother's Day to all of our mothers, and have a meaningful Memorial Day.



*Andy Nemann*

Andy Nemann, Managing Editor

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## DIGITAL HIGHLIGHTS

### MS MEETING

PN will be with the Paralyzed Veterans of America Multiple Sclerosis (MS) Committee late this month in Phoenix for the 2025 Consortium of MS Centers Annual Meeting set for May 27-31. Visit the website for photos, articles and more from the meeting.

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# PVA from the TOP

ROBERT L. THOMAS JR.  
NATIONAL PRESIDENT

## Congressional Testimony

**Each March, Paralyzed Veterans of America's (PVA) national president is afforded an opportunity to speak before a joint session of the House and Senate Committees on Veterans' Affairs.**

The national president's testimony is an invaluable opportunity to speak directly with congressional leaders and instill in them the importance of veterans' health care, benefits, civil rights and caregiver support.

Current PVA National President Robert L. Thomas Jr., provided his testimony at the March 4 hearing. It's the tradition of *PN* to publish the president's oral testimony from this hearing. The following is Thomas' oral testimony.

"Chairman [Jerry] Moran, Chairman [Mike] Bost and members of the committees, thank you for the opportunity to testify on behalf of the tens of thousands of veterans with spinal cord injuries and disorders [SCI/D].

"Today, I want to focus on PVA's top priority: preserving VA's [Department of Veterans Affairs] specialty care system. Specifically, the VA's preeminent system of care for veterans with spinal cord injuries and disorders. On more than one occasion, I have testified before these committees about our concerns that the SCI/D system of care is being slowly starved of staffing, infrastructure upgrades and funding needed to ensure its survival. Not for the sake of VA, but for the sake of the veterans it serves.

"My friend, Rick, a fellow PVA member, received care in the community for eight years for his SCI [spinal cord injury] until he was introduced to VA's SCI/D system of care.



COURTESY OF PARALYZED VETERANS OF AMERICA

Flanked by supporting Paralyzed Veterans of America (PVA) members, PVA National President Robert L. Thomas Jr., seated at the table, testifies before a joint session of the House and Senate Committees on Veterans' Affairs March 4 in Washington, D.C.



Once under VA care, his health improved. He believes he would have died if he hadn't begun to receive specialized health care from VA medical professionals who understand our injuries and illnesses.

"Despite best intentions, community health care providers aren't as well-equipped to meet our complex needs. That's why so many veterans, like myself, choose care provided by the VA. The entire model is designed with us in mind. That's why thousands of PVA members and their families and supporters have signed a petition opposing any efforts to dismantle the VA's SCI/D system of care and the lifesaving services it provides. We choose VA.

"Unfortunately, this system is facing challenges of epic proportions, and the consequences, if not addressed now, will prove devastating for veterans with specialized health care needs. For example, one of the 25 SCI/D centers can only use half its beds because staffing vacancies exceed 50 percent. The leadership there recently denied again the center's request to backfill a resignation. As a result, overtime is increasing, and we expect additional resignations due to burnout and/or closure of additional SCI beds.

"Staffing shortages in the system aren't new. The SCI/D system of care has been short hundreds of nurses for years, with total staffing vacancies hovering around 35 percent. The department has been concealing its vacancy problems through the use of overtime, which, if taken away, may reveal much more serious staffing issues. Without proper staffing, veterans may be forced to accept care in the community, even when it is not the quality or type of care they would receive at a VA facility, and most importantly, when it is not their decision to do so.

"In addition to staffing shortages, the system also continues to suffer from infrastructure deficiencies. The average age of an SCI/D center is nearly 40 years old. Consequently, we saw major incidents at several centers last year. For example, a plumbing system failure at one facility flooded half of the center. It took one month to repair the system, restore the impacted areas and move patients back into the SCI/D center.

"We call on Congress to invest the necessary funds to ensure sufficient specialty care staffing and address infrastructure deficiencies to meet the demand for care. For those of us with catastrophic injuries, VA is the cornerstone of our care. The cost of inaction is clear — the lives of veterans like Rick and myself, and thousands of others living with SCI/D, are at stake.

"In recent weeks, there have been many changes in federal government staffing and funding. While we understand and generally support the underlying desire for [VA] to streamline access to care and benefits, the arbitrary and haphazard way that these efforts are being approached is failing that mission and harming veterans.

"PVA members are concerned that VA-provided care won't be available in the future and that the lifesaving research will be curtailed. Even though many clinical providers may be protected by staffing changes, not all are, including recreational therapists who help teach veterans with SCI/D how to reengage in the social part of community following a catastrophic disability. They are equally concerned about access to benefits like home modifications being delayed because of new staffing shortages.

"How can we expect physicians, nurses, claims raters, vocational rehab counselors and other staff to be focused on their mission to care for the veterans while the specter of losing their jobs hangs over their heads [or] they carry the workload of multiple positions? They can't. As the body charged with VA oversight, I urge you to act before veterans are harmed any further.

"I would be happy to answer any questions you may have." ■

"... the arbitrary and haphazard way that these efforts are being approached is failing that mission and harming veterans."



No doctor recommends isolation as a means to heal or rehabilitate.

## Out Of Isolation

**Solitary confinement is a form of punishment** and sometimes torture, and regardless of why it's used, it can have severe negative psychological effects.

Debates are ongoing about the ethics and legality of solitary confinement, but I believe most people will agree that it's cruel. So, why do we do it to ourselves?

Because sometimes we just need a break from the kids. After spending the day with my two daughters, I look forward to some "me time" after they go to bed. I need that daily dose of solitude to maintain my sanity, but sometimes too much solitude can lead us into some pretty dark places.

In 1991, I was in the intensive care unit (ICU) at Balboa Naval Hospital in San Diego. I had just broken my neck in a parachuting accident, and I couldn't feel or move anything below my chest. My head and neck were immobilized with something only Dr. Frankenstein or Pulitzer Prize-winning cartoonist and inventor Rube Goldberg could create.

I had cranial tongs affixed to my skull with pointed screws and some kind of cervical traction device that relied on a system of pulleys and weights hanging behind my head. I certainly wasn't going anywhere anytime soon. I was confined to my bed and surrounded by curtains.

The curtains provided a sense of privacy, although they did nothing to buffer the incessant clamor of a hectic ICU. The noise was inescapable. I don't remember what kind of pain medications I was given, but I do remember my imagination ran wild. I could hear the conversations among the clinical staff, even though their medical jargon was foreign to me. I remember hearing a woman crying and expressing grief when the patient in the neighboring bed passed away. Cell phones and Wi-fi didn't exist back then, so I had no contact with the outside world. I asked myself, "Does my family know that I'm here?"

An overwhelming sense of isolation began to take root, followed by paranoia. I

began to question my treatment and wondered why my doctor had condemned me to solitary confinement. A state of fight-or-flight was emerging, which conjured up uninvited memories of some training I had gone through while in the military.

Just a few months earlier, I had attended the Navy's Survival, Evasion, Resistance and Escape (SERE) training program. Perhaps the most memorable part of SERE was the so-called "POW (prisoner of war) camp experience." It simulated captivity and the psychological challenges of being held against one's will.

A hood was placed over my head, and I was jammed into a 3-by-3 foot box made of concrete blocks. Confined to such a tiny space while wearing the hood, I was unable to move or see. To make matters worse, a recording of a screaming baby was played incessantly, all while I was deprived of food, water, sleep and human interaction.

By the following day, I had convinced myself that I didn't like being confined to little boxes, so I schemed a plan to escape. However, before I could carry out my great escape, the training came to an end, and I was rewarded with a peanut butter and jelly sandwich.

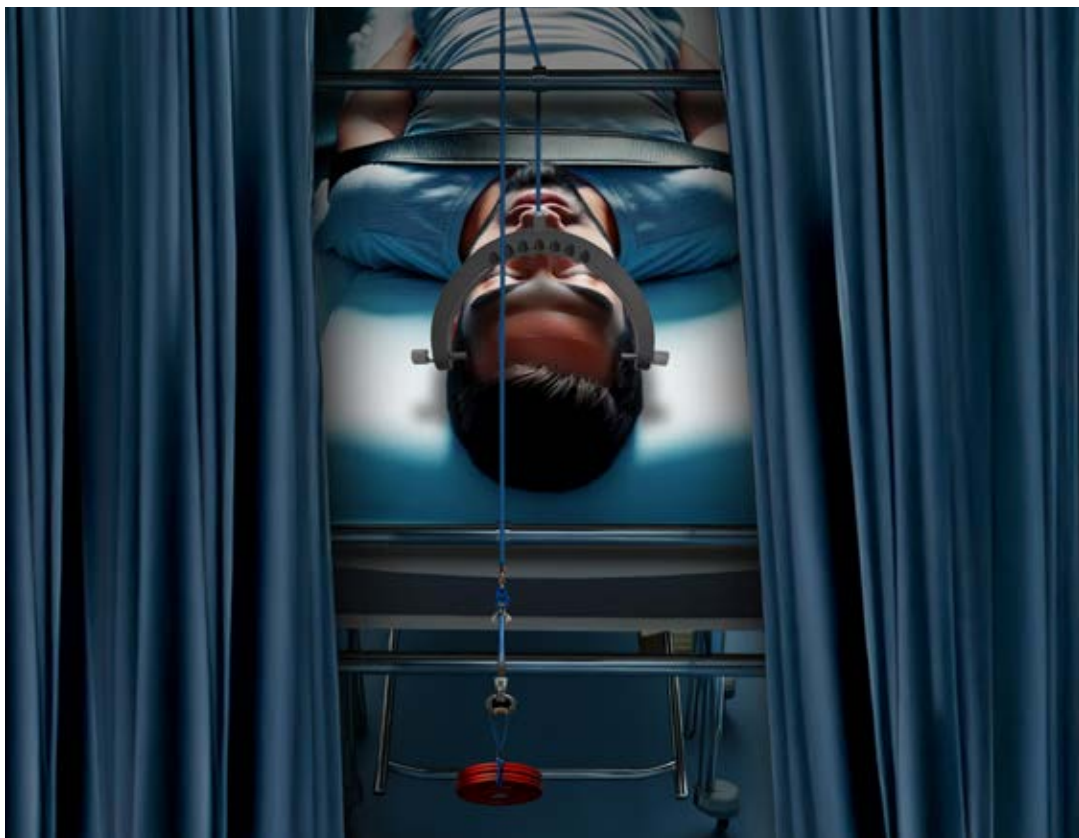
That training was supposed to prepare me in the event I was captured and held captive by an enemy. But what if I was being held captive in a hospital?

Well, with that in mind, I schemed a plan to escape from Balboa Naval Hospital. First, I had to disconnect myself from that medieval contraption around my head and neck; second, jump out of bed; third, bust through those flimsy curtains; and lastly, rendezvous with my friends at McP's Irish Pub and brag about my brilliant escape while enjoying a peanut butter sandwich.

The first part of my planned escape went well, but the second part proved to be more problematic. Who knew getting out of bed with a broken neck could be so difficult? The sound of the weights hitting the floor alerted the nurses, so any hope of celebrating with my friends that night was lost.

Not to be deterred, a second attempt was made the following day with the same results.





"Loneliness expresses the pain of being alone, and solitude expresses the glory of being alone."

— Paul Tillich,  
theologian and  
philosopher

It was determined that I was not being compliant and needed to be restrained for the duration. Fearing being left alone with my hands tied to the side bed rails, I tried to negotiate with them. I promised to cease all attempts to escape my cell, as long as a nurse was at my bedside 24/7. Needless to say, I was restrained.

After four weeks of captivity and two surgeries, I was transferred to the Department of Veterans Affairs' spinal cord injury (SCI) center located just a few miles away to begin my rehabilitation.

I was placed in a large room flooded with sunlight coming through a wall of windows. It sure beat the light from the florescent tubes above my bed in the ICU. And my new digs included an en suite bathroom with a shower — something that had eluded me during the previous four weeks.

There were three other patients assigned to my room who were willing to share their experiences, and volunteers visited from the local chapter of Paralyzed Veterans of America. Sure, there were curtains for privacy, but they were rarely utilized. Despite the constant flow of people, the noise levels were negligible, and nobody was having a near-death crisis.

The new vibe was positive, and my arrival at the SCI center brought an end to the month-long saga of isolation and all the crazy stuff

that came with it. It had been a long time since I had felt that optimistic about anything.

It's embarrassing to put all these crazy memories in writing, but I have to admit it's been good therapy. During those first four weeks of being a quad, my emotional state was very unstable as a result of the isolation. My behavior in the ICU might be considered by some as irrational or silly, but when it was happening in real time, it was absolutely frightening.

No doctor would recommend isolation as a means to heal or rehabilitate. Post-traumatic stress disorder (PTSD) symptoms are common among those of us with a traumatic SCI. PTSD symptoms can lead to social isolation, which in turn worsen PTSD symptoms; we're inadvertently creating a self-reinforcing loop.

Nowadays, when I see my fellow patients hide behind their curtains, I try not to judge. I'm guessing it's their way of coping with excessive worry. But that isolation can also lead to serious and unintended consequences.

I know there can be many reasons why patients choose not to venture beyond their curtains. I just hope someone is paying attention.

As always, please let me know your thoughts at [al@pvamag.com](mailto:al@pvamag.com). ■

## PVA Teams With Lancôme

**Paralyzed Veterans of America (PVA)** is teaming with one of the world's leading cosmetics companies to help female veterans and other women with disabilities.

PVA and Lancôme announced a partnership March 3 that reflects their shared commitment to ensuring women with disabilities feel seen, heard and empowered. The partnership includes empowerment events, adaptive products and an in-store activation.

"I believe that every woman deserves to be seen for who they truly are — a whole person with strength, beauty and endless potential," says Lancôme USA General Manager Ramzy Burns in a press release. "That is what PVA and Lancôme's partnership is all about. Caring for others is in our DNA, so prioritizing what matters to this ever-growing community is important to us. This partnership is more than a campaign or pledge of

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support. It is a reflection of our continued commitment to making the beauty industry a force for positive change."

This year, Lancôme and PVA will implement two initiatives as part of their partnership. Lancôme will sponsor PVA's Women Veterans Empowerment Retreat that is set for October in Minneapolis. The cosmetic giant will also celebrate and support

the strength of women athletes through sponsorship of July's National Veterans Wheelchair Games in Minneapolis.

Lancôme worked with PVA members on the beta test for its groundbreaking HAPTA device, a handheld, ultra-precise smart makeup applicator for users with limited hand and arm mobility.

For more information on the partnership, visit [lancome.com](http://lancome.com) or [pva.org/lancome](http://pva.org/lancome).



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**The HAPTA device has built-in smart motion controls, which include a stabilizing handle.**

## VA Layoffs?

**A potential plan** for a large reduction in Department of Veterans Affairs (VA) staffing is being called "frightening" by Paralyzed Veterans of America (PVA).

Several news agencies, including Reuters and The Associated Press, reported in early March that an internal memo showed the VA is planning to cut more than 80,000 jobs as early as June. The reported job cuts would return the VA to 2019 staffing levels of about 400,000.

PVA CEO Carl Blake says more information is needed on the reported staffing cuts, but they could have a big effect on veterans.

"Although there is a great deal of context and detail not yet available, the VA's plans to reduce its workforce by tens of thousands is a frightening proposition for catastrophically disabled veterans," Blake says in a March 5 press release. "While PVA believes that there is an opportunity to streamline some operations within the VA, it also feels it is vital to understand that the delivery of critical health care and earned benefits requires some degree of administrative support to function successfully. Staff cuts for the sake of cuts are unacceptable. We have already seen the consequences of previous arbitrary decisions across the

VA and the dire impact they have on veterans.

"PVA's greatest concern is the impact that such a massive reduction could have on the timely delivery of life-saving, life-sustaining health care and benefits earned through honorable service, particularly for our members — veterans with spinal cord injuries or diseases, like ALS [amyotrophic lateral sclerosis] and MS [multiple sclerosis]. The VA's SCI/D system of care is unique and specialized in a way unmatched in the private sector. This system must not be compromised by any further reduction efforts, and all previous reductions impacting the system should be reversed — the lives and well-being of our nation's veterans are at stake."

Responding to the reports, VA Secretary Doug Collins wrote an opinion piece in the March 6 edition of *The Hill*, where he says America's veterans are owed a "solution" and any changes would be done by a "thorough and thoughtful review."

For more information, visit [pva.org](http://pva.org).

## Election Survey


**Paralyzed Veterans of America (PVA)** is conducting a survey on accessible voting.

The study aims to learn more about the voting experience of people with disabilities in the 2024 general election. The



feedback received from this survey will inform PVA on how to educate members as they face accessibility barriers in voting.

The information will also provide valuable insights and guide preparation for future webinars and other resources related to voting accessibility.

To take the survey, visit [surveymonkey.com/r/63WS8TG](https://surveymonkey.com/r/63WS8TG). 



COURTESY OF PARALYZED VETERANS OF AMERICA

## VA Care & Congress

Protecting the specialized care of veterans with spinal cord injury and disease took center stage on Capitol Hill in March, as Paralyzed Veterans of America (PVA) members met with congressional leaders to discuss staffing shortages at the Department of Veterans Affairs. At left, PVA CEO Carl Blake, with hand on the table, and other PVA leaders meet March 13 with Sen. Richard Blumenthal (D-Conn.), seated at head of the table, ranking member of the Senate Committee on Veterans' Affairs.

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## Outdoor Accessibility

**As the weather gets warmer,** more people, including people with disabilities, want to go outside and spend time in the great outdoors.

Historically, accessibility barriers have too often prevented people with disabilities from enjoying outdoor areas and participating in outdoor recreation. The Americans with Disabilities Act, Architectural Barriers Act, Section 504 of the Rehabilitation Act, agency regulations and state policies are supposed to work to ensure everyone, regardless of ability, can enjoy the benefits of nature and outdoor recreational activities.

Despite decades of progress, barriers continue to exist as agencies try to balance accessibility with preserving the natural integrity of outdoor areas. In preparation for the summer, Paralyzed Veterans of America (PVA) would like to bring awareness to recent regulatory

and legislative efforts focused on increasing outdoor accessibility.

### The EXPLORE Act

Last December, the Expanding Public Lands Outdoor Recreation Experience (EXPLORE) Act, a bipartisan package of public lands recreation bills, was passed and signed into law.

The EXPLORE Act seeks to improve recreation opportunities and facilitate greater access to federal public land. It contains provisions designed to create opportunities for more access to outdoor recreation for veterans and people with disabilities.

Many trails and activities on federal public lands are inaccessible for families and people with disabilities. The Access for People with Disabilities provisions of the EXPLORE Act require comprehensive and thorough assessments of outdoor recreation facilities on federal recreational lands to determine their accessibility.

This includes assessments of high-priority trails to identify oppor-

tunities to increase accessibility. The provisions also require the secretary of the interior to enter into partnerships with entities to make modifications to trails to enhance recreational experiences for people with disabilities who use assistive technology.

The EXPLORE Act also requires the selection of locations for the development of new accessible trails that comply with the Architectural Barriers Act and Section 504 of the Rehabilitation Act. Furthermore, the act requires the creation of new accessible recreation opportunities, like camp sites and water activities, in land managed by the National Park Service (NPS), U.S. Forest Service, Bureau of Land Management and U.S. Fish and Wildlife Service.

Additionally, the EXPLORE Act includes provisions to promote outdoor recreation for military service members and veterans. The secretary is required to work with the secretary of veterans affairs (VA) and the secretary of defense to develop and disseminate educational materials on opportunities for access to federal recreational lands to members of the armed forces and veterans.

The act even requires the establishment of a military veterans outdoor recreation liaison at the VA, the Department of Agriculture and the Department of the Interior. The liaison's roles include implementing recommendations to identify new opportunities to coordinate with agencies, addressing identified barriers and facilitating the use of federal recreational land for promoting wellness for veterans.

Moreover, the act demonstrates Congress' commitment to increasing access by calling for the creation of a strategy to increase visits to federal recreational lands by members of the armed forces and veterans. The act

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COURTESY OF CODY ROUX

also requires strong encouragement to hire veterans in all positions related to the management of federal recreational lands, showing a deep commitment to ensuring not only access, but also opportunities for employment following military service.

## NPS Regulations

The NPS recently requested comments on two rulemakings that would have an impact on accessibility.

The first was a request for comments on a director's order concerning NPS policies and procedures governing accessibility of NPS facilities, programs and services. PVA submitted comments on this rulemaking to encourage NPS to provide clear information to the public on rules about wheelchair usage in federal wilderness areas.

PVA's comments also recommend that the NPS advisory group conduct outreach to national organizations representing the disability community and federal agencies with disability programs.

Next, the NPS issued a Notice of Proposed Rulemaking that established a framework for the use of powered micromobility devices. The framework proposed a definition for powered micromobility devices that would include devices such as Segways, hoverboards and electric scooters.

When unregulated, these devices can cause accessibility barriers for people with disabilities by blocking accessible routes. NPS proposed prohibiting these devices in its system. Micromobility has become popular in recent years, and that popularity doesn't appear to be slowing down.

It's important that agencies explore exceptions, however, for people with disabilities who use adaptive devices to participate in outdoor recreation. Regulations meant to benefit park system users can address some barriers to access while inadvertently creating new ones.

PVA is heartened to see an increased prioritization of outdoor accessibility. Participation in outdoor recreational activities contributes to the inclusion of people with disabilities in society.

Moving forward, PVA will continue to seek opportunities to advocate for improvements that will help ensure access for members to more outdoor recreational opportunities.

*Anthonya James is a PVA advocacy attorney in Washington, D.C. ■*



# research **update**

JIM LYNCH

## BCI Provides “Unprecedented” Level Of Control

**A brain-computer interface** surgically placed in a research participant with tetraplegia has provided an unprecedented level of control over a virtual quadcopter — just by thinking about moving his unresponsive fingers.

The technology divides the hand into three parts: the thumb and two pairs of fingers (index and middle, ring and small). Each part can move both vertically and horizontally. As the participant thinks about moving the three groups, at times simultaneously, the virtual quadcopter responds, maneuvering through a virtual obstacle course.

It’s an exciting next step in providing those with paralysis the chance to enjoy games with friends, while also demonstrating the potential for performing remote work.

“This is a greater degree of functionality than anything previously based on finger movements,” says Matthew Willsey, PhD, University of Michigan assistant professor of neurosurgery and biomedical engineering, and first author of a research paper published in January in *Nature Medicine*.

The testing that produced the paper was conducted while Willsey was a researcher at Stanford University in California, where most of his collaborators are located.

### New Options

While there are noninvasive approaches to allow enhanced video gaming, such as using electroencephalography (EEG) to take signals from the surface of the user’s head, EEG signals combine contributions from large regions of the brain. The authors



A screenshot of the game display shows the quadcopter following a green path around the rings. The inset shows a hand avatar. The neural implant records from nearby neurons, and algorithms determine the intended movements for the hand avatar. The finger positions are then used to control the virtual quadcopter.

believe that to restore highly functional fine motor control, electrodes need to be placed closer to the neurons. The study notes a sixfold improvement in the user’s quadcopter flight performance by reading signals directly from motor neurons versus EEG.

To prepare the interface, patients undergo a surgical procedure in which electrodes are placed in the brain’s motor cortex. The electrodes are wired to a pedestal that is anchored to the skull and exits the skin, which allows a connection to a computer.

“It takes the signals created in the motor cortex that occur simply when the participant tries to move their fingers and uses an artificial neural network to interpret what the intentions are to control virtual fingers in the simulation,” Willsey says. “Then, we send a signal to control a virtual quadcopter.”

The research, conducted as part of the BrainGate2 clinical trials, focused on how these neural signals could be coupled with machine

learning to provide new options for external device control for people with neurological injuries or disease.

The participant first began working with the research team at Stanford in 2016, several years after a spinal cord injury left him unable to use his arms or legs. He was interested in contributing to the work and had a particular interest in flying.

“The quadcopter simulation was not an arbitrary choice. The research participant had a passion for flying,” says Donald Avansino, co-author and computer scientist at Stanford University. “While also fulfilling the participant’s desire for flight, the platform also showcased the control of multiple fingers.”

### Beyond Games

Study co-author Nishal Shah, PhD, professor of electrical and computer engineering at Rice University in Houston, says, “Controlling fingers is a stepping stone; the ultimate goal is whole body movement restoration.”



Jaimie Henderson, MD, a Stanford professor of neurosurgery and study co-author, says the work's importance goes beyond games. It allows for human connection.

"People tend to focus on restoration of the sorts of functions that are basic necessities — eating, dressing, mobility — and those are all important," Henderson says. "But oftentimes, other equally important aspects of life get short shrift, like recreation or connection with peers. People want to play games and interact with their friends."

A person who can connect with a computer and manipulate a virtual vehicle simply by thinking, he says,

could eventually be capable of much more.

"Being able to move multiple virtual fingers with brain control, you can have multifactor control schemes for all kinds of things," Henderson says. "That could mean anything, from operating CAD software to composing music."

Researchers Nick Hahn, Ryan Jamiolkowski, Foram Kamdar and Francis Willett at Stanford and Leigh Hochberg at Brown University in Rhode Island also contributed to the study.

*Jim Lynch is with the University of Michigan's College of Engineering Communications & Marketing.* ■

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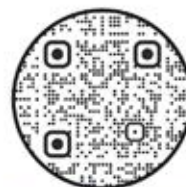
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# veteranadvisor

BRENDA STENCIL, NSO

## My HealtheVet

### The My HealtheVet portal

started as a pilot program at nine Veterans Affairs Medical Centers (VAMC) in 1999. It was launched to the public Nov. 11, 2003, and today, My HealtheVet is accessible to millions of veterans.

My HealtheVet is the Department of Veterans Affairs' (VA) online health care portal, offering secure access to veterans' health information. It's intended to assist veterans with making health care management more convenient, especially for vets who prefer handling tasks online.

The portal contains four areas with multiple options in each one:

- **Pharmacy:** Refill VA prescriptions, track VA prescription delivery and review all past and current medications.
- **Appointments:** Request or self-schedule some appointments, review upcoming community care appointments and review an After-Visit Summary from a previous appointment.
- **Messages:** Communicate privately and securely with the VA health care team online. Organize messages in folders and download and print messages.
- **Health records:** View VA health information (lab and test results, allergy information, vaccine information, provider notes and care summaries, vitals and health conditions).

## Transition

Since its inception, veterans have been required to access My HealtheVet with a specific user ID and password. Access to other VA sites requires a separate login.



MYHEALTH.VA.GOV

In October 2023, the VA announced the My HealtheVet portal would transition from its current website to va.gov. The VA stated veterans wouldn't lose any stored information, and VA health care and benefits could be managed by phone, by mail or in person.

The transition to va.gov is intended to provide veterans with one-stop shopping to manage their VA health care on the same website where they already access benefits and services.

Last July, in continuation of those changes, the VA announced My HealtheVet and DS Logon sign-in options would be phased out and veterans would need to start using a login.gov or id.me login.

Originally, Jan. 31 was the deadline the VA set to shut down My HealtheVet logins and passwords. The VA then extended the deadline for veterans to transition to the new online login system to March 4.

While many veterans have successfully moved to login.gov and id.me access, the VA expressed its intention to use the additional time to ensure as many veterans as possible made the switch before the

legacy My HealtheVet username and password system became permanently retired.

## Which One To Use?

Veterans trying to decide whether to use login.gov or id.me should know that there are differences.

One of the biggest differences is that login.gov is maintained by the U.S. government, while id.me is run by a non-government provider for the VA. Both meet modern security standards and protect your data.

A full description of each login system and the requirements needed to set up an account can be found in



the Veteran Advisor department of April's issue of PN.

Another key point about accessing VA benefits and information is that after Sept. 30, veterans will no longer be able to sign in with a DS Logon username and password.

## New Tools

When signing into va.gov and by selecting My HealtheVet in the main navigation, the veteran will now start on the new My HealtheVet on va.gov landing page.



This page has links to essentially the same health tools that were previously available. The VA has also indicated it will be adding new tools and features veterans have specifically asked for, such as the ability to file a travel claim, reorder a medication or quickly find a specific lab result without having to download an entire medical record.

The VA also promises improvements so My HealtheVet on va.gov is easier for all veterans to use, including those who are blind or have low vision and/or use a screen reader or other assistive device.

Those who haven't utilized their electronic VA health care interface may create an account at va.gov/sign-in/?oauth=false.

Many websites can be difficult to access or create accounts due to factors such as confusing navigation, strict verification processes or technical issues with the site itself, making it frustrating for veterans to navigate and register.

Veterans have several options for any questions or assistance setting up or accessing their personal account:

- login.gov: login.gov/help/
- id.me: help.id.me/hc/en-us
- My HealtheVet: Contact the help desk at 877-327-0022 or 800-877-8339 (TTY), 7 a.m. to 7 p.m. (Central Time) Monday through Friday

For help with this or any benefits questions, contact your local Paralyzed Veterans of America (PVA) national service officer (NSO) from the roster on page 33.

Information for this article was compiled from public sources such as va.gov, login.gov and id.me.

*A 27-year veteran of the Navy, Brenda Stencil has been a PVA NSO in Milwaukee since 2022. ■*

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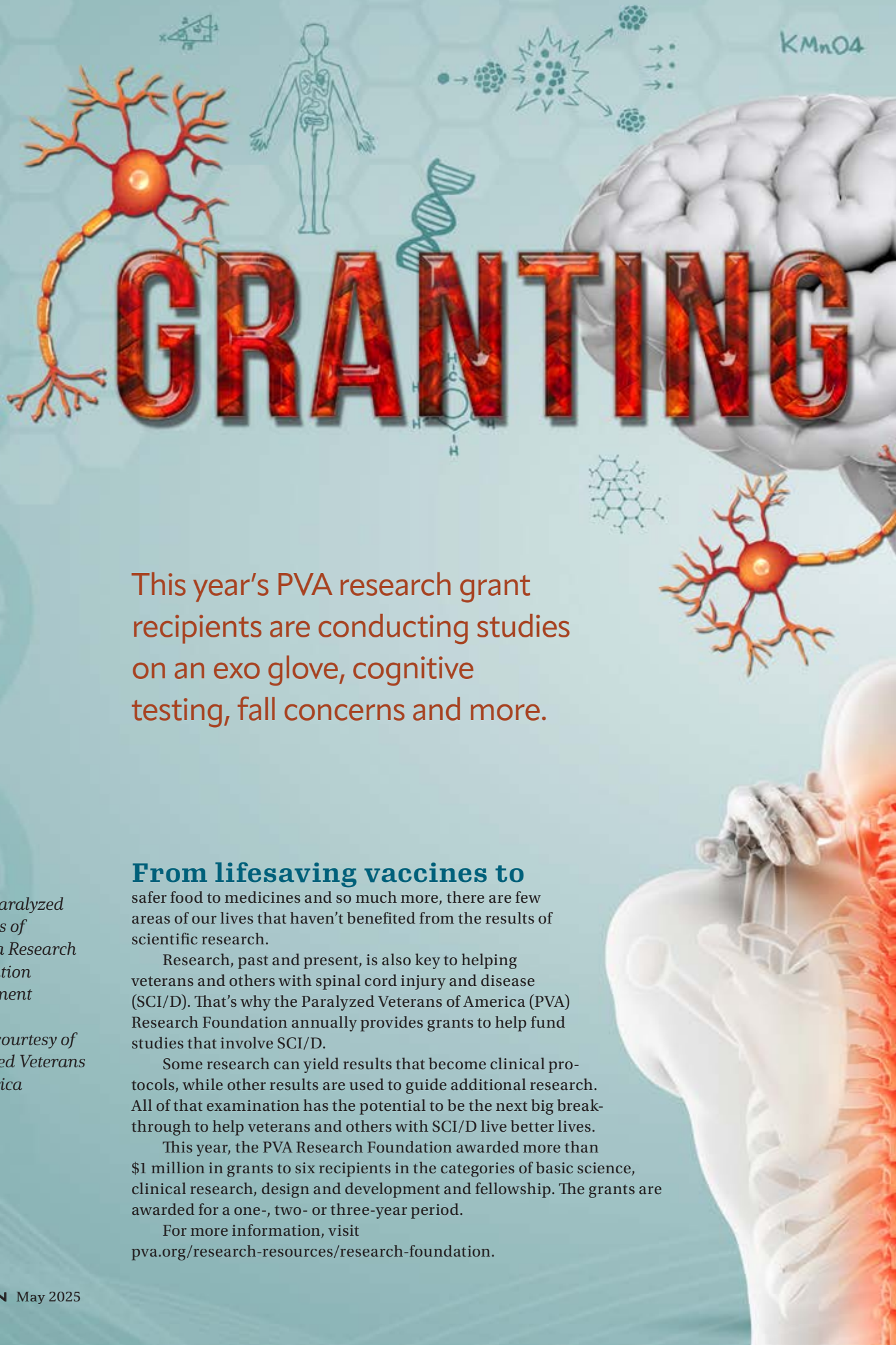
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## What's your favorite place for an accessible vacation?



PN is planning an upcoming article 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.



# GRANTING

This year's PVA research grant recipients are conducting studies on an exo glove, cognitive testing, fall concerns and more.

*by the Paralyzed  
Veterans of  
America Research  
& Education  
Department*

*photos courtesy of  
Paralyzed Veterans  
of America*

## From lifesaving vaccines to

safer food to medicines and so much more, there are few areas of our lives that haven't benefited from the results of scientific research.

Research, past and present, is also key to helping veterans and others with spinal cord injury and disease (SCI/D). That's why the Paralyzed Veterans of America (PVA) Research Foundation annually provides grants to help fund studies that involve SCI/D.

Some research can yield results that become clinical protocols, while other results are used to guide additional research. All of that examination has the potential to be the next big breakthrough to help veterans and others with SCI/D live better lives.

This year, the PVA Research Foundation awarded more than \$1 million in grants to six recipients in the categories of basic science, clinical research, design and development and fellowship. The grants are awarded for a one-, two- or three-year period.

For more information, visit [pva.org/research-resources/research-foundation](http://pva.org/research-resources/research-foundation).





# RESEARCH

ILLUSTRATION BY KERRY RANDOLPH © GETTYIMAGES/  
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## Basic Science

**Michael Fehlings, MD**

**University Health Network, Toronto**

*Restoring Functional Synaptic Connectivity  
to Augment the Effectiveness of Targeted  
Rehabilitative Training Following  
Cervical Spinal Cord Injury*

**\$200,000**

Most spinal cord injury (SCI) patients retain neural tissue near the site of injury, but recovery is limited by a disruption of functional neuron connections, or synapses.

This limits arm and leg recovery and impedes vital functions such as the respiratory, cardiovascular and immune systems. To restore these functional circuits, the researchers are developing a clinically relevant approach through a Food and Drug Administration (FDA)-approved and repurposed drug, torsemide, with targeted forelimb rehabilitation.

For the mechanism part of the investigation, the researchers hypothesize that torsemide will reduce the aberrant chloride concentration disrupting inhibitory signaling in neural circuits post-SCI, which will enhance rehabilitation-induced improvements in signal propagation.



**Michael Fehlings, MD**



By restoring communication in these neural circuits, this approach hopes to improve movement, sensation and overall function in SCI patients.

This treatment strategy holds significant translational relevance, with the potential to greatly impact SCI patients' lives.

### Clinical Research

**Christopher DeSouza, PhD**  
**University of Colorado, Boulder, Colo.**  
*Vascular Consequences of Neurogenic Obesity in Adults with SCI*  
**\$200,000**



Christopher DeSouza, PhD

Adults with SCI undergo major changes in body composition that result in a high prevalence of obesity. Obesity is considered to be a major factor contributing to the increased risk of heart attack and stroke in individuals after SCI.

From a clinical and public health perspective, supporting an individual's neurologi-

cal recovery starts by preventing secondary complications from early post-injury and throughout life. The study's primary purpose is to determine the impact of obesity on how well blood vessels function in adults with SCI.

Impaired vascular (blood vessel) function leads to heart attack and stroke. Greater understanding of the vascular consequences of obesity in adults with SCI is critical to optimizing clinical care to reduce the risk of heart attack and stroke in adults after injury.

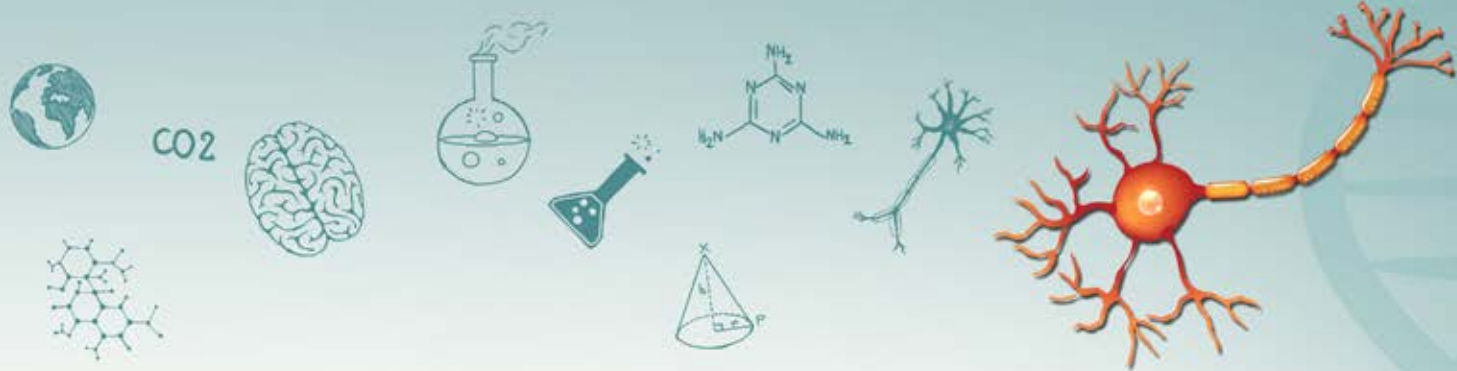
**Laura Rice, PhD**  
**University of Illinois, Champaign, Ill.**  
*Assessment and Prediction of Fall Concerns Among People with SCI and MS who use Wheelchairs and Scooters*  
**\$200,000**

Concerns about falling (CaF) are a major issue for people living with SCI and multiple sclerosis (MS) who use wheelchairs or scooters every day.



Laura Rice, PhD





These worries can keep people from participating in important activities in their homes and communities that they either need to do or enjoy. This project aims to create an outcome measure that clinicians and researchers can use to effectively assess CaF.

By accurately evaluating CaF, clinicians and researchers will be better equipped to develop educational programs that help manage these concerns, ultimately supporting people living with SCI and MS who use wheelchairs in achieving their desired activities at home and within their community.

## Design & Development

**Derek Wolf, PhD**

**University of Cincinnati**

*Cooperative design of a user-friendly FES-integrated passive exo to restore grasping ability in individuals with SCI/D*

**\$199,797**

This project aims to develop a functional electrical stimulation (FES)-integrated passive exo glove for individuals with SCI/D to assist them in independently performing daily grasping tasks.

The developed device will combine FES, which uses electrical signals to activate muscles, with a passive exoskeleton to coordinate hand movements.

Working with a collaborative team of end-users, clinicians and engineers, researchers will follow a user-centered, iterative design process to develop and validate a device that is easy to use, functional and comfortable for daily at-home use.

The design process will follow FDA guidelines with a focus on translating the technology outside the research lab. The cooperative design process will result in a novel assistive device for at-home, independent use by individuals with SCI/D.

## Fellowship

**Manrui Zhang, PhD**

**Feinberg School of Medicine**

**Northwestern University, Evanston, Ill.**

*Engaging Veterans with Spinal Cord Injury in Robust Cognitive Testing: Accommodation Solutions and Implementation Determinants to Using NIH Toolbox Cognition Battery during Inpatient Rehabilitation*

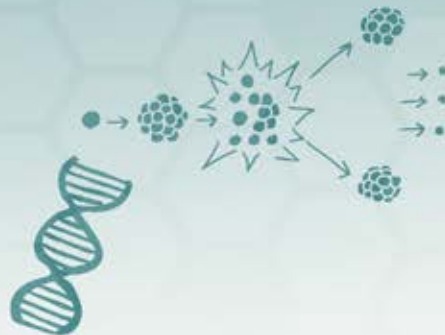
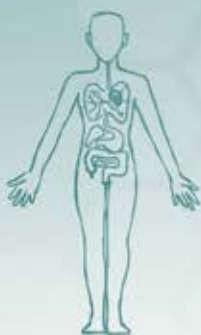
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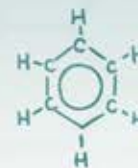
Derek Wolf, PhD



Manrui Zhang, PhD



$KMnO_4$



People with SCI are at 13 times greater risk for cognitive impairment. This risk can be even higher among veterans due to the high prevalence of traumatic brain injury and post-traumatic stress disorder.

Cognitive impairment significantly undermines the effectiveness of SCI rehabilitation, which requires intensive learning of new skills to achieve optimal outcomes. While a clinical guideline recommends reliable cognitive testing during inpatient rehabilitation, standardized cognitive tests were not commonly implemented during SCI rehabilitation.

Most tests are difficult to use for people with SCI in a fast-moving clinical environment because of accessibility and implementation challenges due to motor impairment, pain and fatigue.

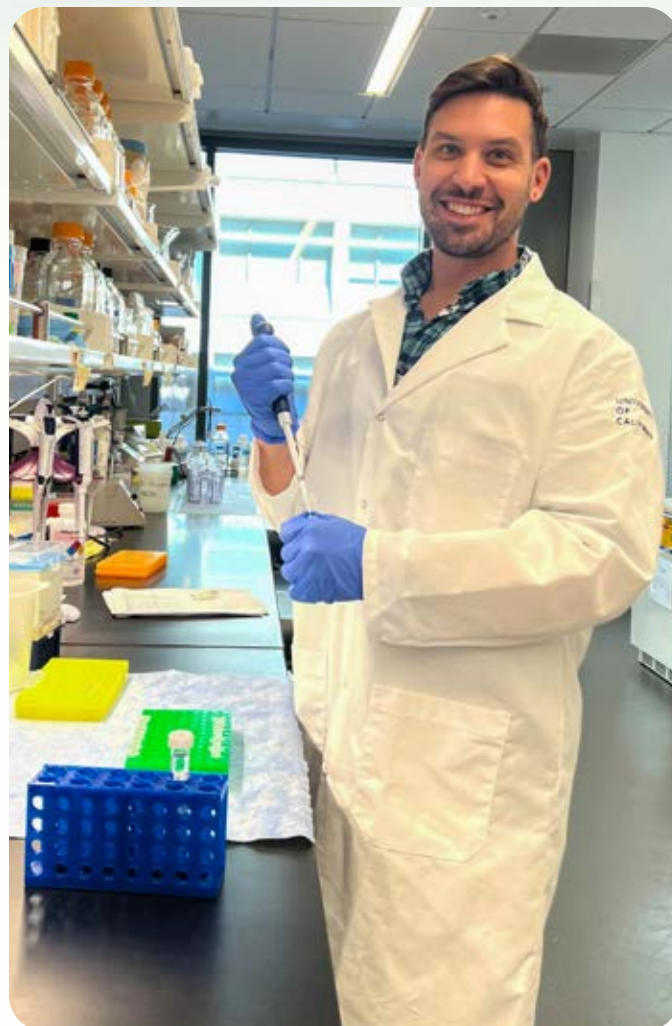
This proposed research aims to generate feasible accommodation solutions and an implementation plan to facilitate accessible and scalable cognitive testing in SCI rehabilitation, focusing on the National Institutes of Health Toolbox Cognition Battery, a promising tool to engage veterans with SCI in reliable cognitive testing.

**Jason Gumbel, PhD**  
**University of California-San Francisco**  
*Mechanisms of Kidney Dysfunction Following SCI*

**\$150,000**

SCI commonly causes bladder, kidney and cardiovascular dysfunction, all of which are high-priority quality of life measures.

Currently, little is known about the mechanisms of kidney dysfunction following SCI. Cardiovascular and renal function are two systems that can influence the other. SCI



Jason Gumbel, PhD

negatively impacts both cardiovascular and renal health independently, resulting in a potential cyclical dysfunctional relationship where one system can negatively influence the other.

The study's overall goal is to understand the impact of SCI on kidney function and test potential therapeutic strategies to see if treatment of one system can improve the other. ■



# Nominations Now Open



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Questions? Contact [chris@pvamag.com](mailto:chris@pvamag.com).

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# Deep In The Heart of Texas

A vibrant music scene, mouthwatering barbecue and more await as the PVA Annual Convention rolls into Austin.

by Andy Nemann

## It's not often attendees

of the Paralyzed Veterans of America (PVA) Annual Convention can say they're visiting two capitals at the same time, but they can this month in Austin, Texas.

The capital of the Lone Star State and the Live Music Capital of the World welcomes the 79th annual PVA convention to the Hilton Austin May 13–16. Making its first visit to Austin, the PVA convention has made four previous stops in Texas, including the last one in 2011 in The Woodlands outside of Houston.

Obviously, the purpose of this gathering is the business of PVA. The agenda includes guest speakers, voting on resolutions, a budget and

electing the executive committee (candidate statements were featured in the April issue of *PN*). Of course, business won't last all day, and it's important to relax and recharge.

A great way to unwind is by exploring one of the country's most vibrant cities. The home to the University of Texas (UT), Austin combines the vibe of a college town with the offerings of a large metropolitan city, as well as providing a gateway to the beautiful Texas Hill Country.

The Hilton Austin's location in the heart of downtown provides a perfect location from which to check out the city's famed music scene, tasty food offerings, rich culture, one-of-a-kind attractions and so much more. These are just a few ideas to get you started.



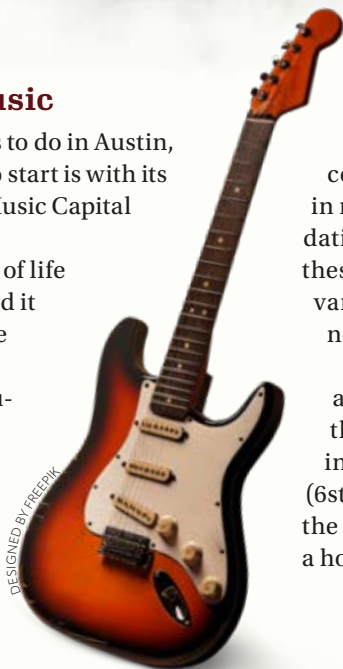




## Move To The Music

When it comes to things to do in Austin, the most logical place to start is with its nickname — The Live Music Capital of the World.

Live music is a way of life in Austin, and you'll find it pretty much every place you go. Large concert halls, small bars, restaurants, outdoor events and even grocery stores and Austin-Bergstrom International Airport are



filled with the sound of almost every style of music.

With so many options available, combined with everyone's different taste in music and the atmosphere, recommendations on where to go are tricky. However, these are few fun and interesting areas with a variety of music and entertainment offerings near the hotel.

One of the first areas you may hear about that's located just a block north of the hotel is the famous (or some might say infamous) 6th Street entertainment district ([6street.com](http://6street.com)). This nine-block area is one of the central hubs for Austin's nightlife, with a host of bars and restaurants. Popular with





Just a block north of the convention hotel, 6th Street is one of the main nightlife centers in Austin, Texas.

UT students, the street is generally closed to traffic most weekend evenings and can get crowded at night.

Another area with plenty to offer is Rainey Street. Located about a half mile south of the hotel along Red River Street, the area is known for its historic bungalows, which have been transformed into bars, restaurants and entertainment spots. The neighborhood includes a food truck park with outdoor dining and nine food trucks.

One more area not far from the hotel is the Warehouse District. Located about four blocks west of the hotel along 5th Street, the district

features many bars and restaurants housed in renovated, antique warehouses. The area is also home to many art galleries, including the Mexic-Arte Museum ([mexic-artemuseum.org](http://mexic-artemuseum.org)).

## Eat Up

There are plenty of fabulous dining options in Austin offering every type of cuisine someone could want, but there are two foods truly synonymous with Texas — barbecue and Tex-Mex.

Barbecue in central Texas is generally focused on slow-smoked beef brisket and ribs that are usually seasoned with a dry rub rather than a sauce. Most places will also offer plenty of other items as well, including sauces, smoked sausage and chicken.

Asking a local for the best barbecue place in town can lead to a wide range of answers and even some heated discussions. So, at the risk of courting controversy, these are just a few places near the hotel that have good recommendations from locals and strong ratings on various travel and food-focused websites:

- Franklin Barbecue ([franklinbbq.com](http://franklinbbq.com))  
One of the top-rated barbecue spots in the country. Expect long lines or order ahead.
- Iron Works ([ironworksbbq.com](http://ironworksbbq.com))  
Located right behind the Austin Convention Center in a historical iron works building.

COURTESY OF VISIT AUSTIN



Rainey Street features a popular food truck park.





Barbecue is a mainstay in Austin, Texas.

- **La Barbecue** ([labarbecue.com](http://labarbecue.com))  
A female-owned, Michelin-rated restaurant that leans more toward the spicy side.
- **Lamberts** ([lambertsaustin.com](http://lambertsaustin.com))  
Located in a historic downtown building, it features an upstairs bar with live music.
- **Terry Black's BBQ** ([terryblacksbbq.com](http://terryblacksbbq.com))  
Named one of the top barbecue places in Texas with a large outdoor seating area.



Beef brisket and ribs are staples of Texas barbecue.

Austin's other culinary distinction is its fiesta of Tex-Mex places. The mix of Mexican fare and Texas zing provides a tantalizing selection of tacos, enchiladas, spicy salsas, margaritas and more. You'll find a vast array of dining options, including food trucks, casual dining, patio dining, fast food and "hole-in-the-wall" places.

Tex-Mex cuisine such as queso is also a big part of the Austin, Texas food scene.



Similar to the barbecue scene, every local will have his or her favorite place for a variety of reasons. These are just a few highly rated places to check out that are close to the hotel:

- **Chuy's** ([chuys.com](http://chuys.com))  
Started in Austin more than 40 years ago, Chuy's features eight signature sauces.
- **El Alma** ([elalmacafe.com](http://elalmacafe.com))  
Featured in *Forbes*, this place mixes classical Tex-Mex with local flavors such as duck and quail.
- **El Arroyo** ([elarroyo.com](http://elarroyo.com))  
Started in 1975 and famous for its witty sign, margaritas and Black Angus beef tacos.

COURTESY OF EL ARROYO



El Arroyo is well known for its witty sign.

- **Joe's Bakery & Coffee Shop** ([joesbakery.com](http://joesbakery.com))  
Open since 1962 and award-winning, it's often packed and serves breakfast all day.
- **Matt's El Rancho** ([mattselrancho.com](http://mattselrancho.com))  
Operating for more than 70 years and famed for its queso dip and enchiladas.

For even more culinary delights in Austin, visit [austin.eater.com](http://austin.eater.com).





This time of year, thousands of bats emerge from under the Congress Avenue Bridge each evening.

parking) features 10 miles of pathway on both sides of the river, offering views of the Austin skyline and surrounding area.

The trail is also a great spot to watch one of Austin's most famous attractions — bats. Each evening around sunset from late March through early fall, thousands of Mexican free-tailed bats emerge from under the Congress Avenue Bridge to begin their nightly flights.

Visit Austin recommends the best time to view the bats is between 7:30 p.m. to 9:45 p.m. There are multiple locations around the bridge to watch this natural wonder, including on the bridge itself. The area can get crowded, so plan to arrive early and make sure to face east for the best view.

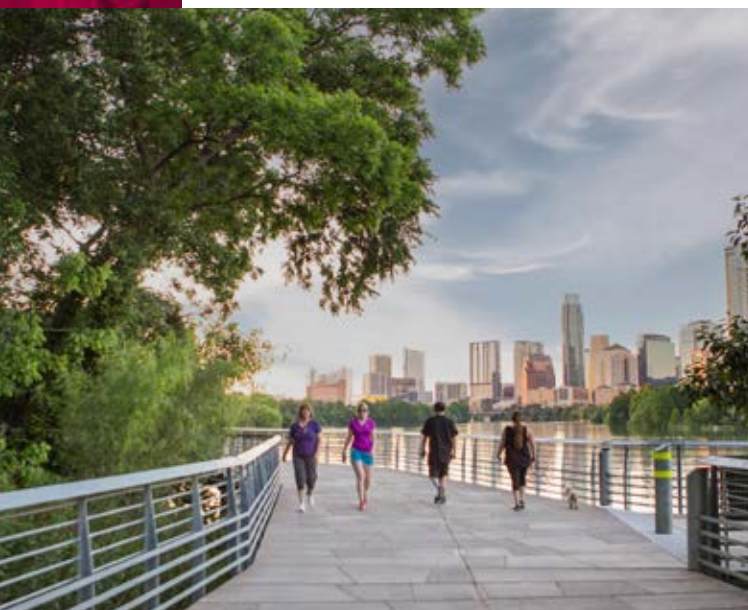
Meanwhile, about a mile farther west along the trail by the distinctive Sailboat Building, the Austin Central Library ([library.austintexas.gov/central-library](http://library.austintexas.gov/central-library)) features a Roof Garden on the top floor with a garden and deck that provide stunning views of the riverfront and south Austin.

Just past the library is a pedestrian bridge. The south side of the riverfront offers even more parks and paths, including the iconic Barton Springs Pool ([austintexas.gov/department/](http://austintexas.gov/department/)

## Go Batty

If all that eating doesn't put you into a deep food coma, try working a bit of it off along a beautiful riverfront and even catch a glimpse of Austin's famed nocturnal residents.

About 10 minutes south of the hotel, Austin's Colorado River front (also called Lady Bird Lake) offers multiple parks and walking paths. The Ann and Roy Butler Hike and Bike Trail ([thetrailconservancy.org/visit-the-trail/maps-](http://thetrailconservancy.org/visit-the-trail/maps-)



TWO PHOTOS COURTESY OF THE TRAIL CONSERVANCY

The Ann and Roy Butler Hike and Bike Trail offers 10 miles of pathways along each side of the Colorado River.



TWO PHOTOS COURTESY OF AUSTIN PUBLIC LIBRARY



The Roof Garden at the Austin Central Library provides a great place to take in views of the city.

barton-springs-pool). Referred to as the crown jewel of Austin, the 3-acre accessible pool is fed from underground springs with an average temperature of 68–70 degrees.

## All The Way With LBJ

If you'd like to explore some indoor attractions, then Austin has you "covered" there, too, with a pair of one-of-a-kind museums.

Anyone interested in presidential history will want to head to the LBJ Presidential Library ([lbjlibrary.org](http://lbjlibrary.org)) on the UT campus. Located about 2 miles north of the hotel, the library is a detailed look at the life and presidency of Lyndon B. Johnson and his famed wife, Lady Bird Johnson.

The 10-story building features innovative, state-of-the-art exhibits that cover every aspect of Johnson's presidency, including the Vietnam War. Among the permanent exhibits are the presidential limousine, a replica of the Oval Office and Lady Bird Johnson's office.

The library is open seven days a week from 9 a.m. to 5 p.m. Admission is \$16 for adults, \$12 for senior citizens and \$8 for retired military.

Another interesting museum can be found in the same area just south of the UT campus. The Bullock Texas State History Museum ([thetoryoftexas.com](http://thetoryoftexas.com)) has told more

COURTESY OF JAY GODWIN



The LBJ Presidential Library includes a replica of the Oval Office.





The Bullock Museum tells the story of Texas.



The 17th century shipwreck of *La Belle* at the Bullock Museum.



A World War II training aircraft featured at the Bullock Museum.

than 9 million visitors the story of Texas with three floors of interactive exhibits.

Each floor is a journey through different eras of roughly 16,000 years of Texas history. Exhibits include the hull from French ship *La Belle* that was part of explorer René-Robert Cavalier, Sieur de La Salle's attempt to establish a colony along the Texas coast and a World War II-era training aircraft produced in Dallas. There's also an IMAX theater showing educational and feature films.

The museum is open seven days a week from 10 a.m. to 5 p.m. Admission is \$15 for adults and \$11 for seniors, students and veterans.

### Discover Even More

All that is barely an appetizer when it comes to the buffet of activities and attractions Austin has to offer.

Besides all the wonderful things happening in the city, Austin is a great starting point to explore the beautiful Texas Hill Country. The region is filled with parks, rolling hills, vineyards, rivers and spring-fed pools.

There's even more beyond that, but whether it's for work, play or both, part of traveling is finding your own fun.

For more general information about visiting Austin, visit [austintexas.org](http://austintexas.org) or [heyaustin.com](http://heyaustin.com). ■





For assistance, please refer to the directory below to identify the Paralyzed Veterans of America (PVA) Service Office nearest you. Also, you may contact the PVA Veterans Benefits Department located at our headquarters in Washington, D.C., at 866-734-0857.

## ALABAMA

VARO, Montgomery  
334-213-3433

## ARIZONA

VARO, Phoenix  
602-627-3311

## ARKANSAS

VARO, North Little Rock  
501-370-3757

## CALIFORNIA (Hawaii, Manila)

VAMC, Long Beach  
562-826-8000, ext. 23774

VARO, Los Angeles  
310-235-7796

VAMC, Mather  
916-843-2602

VAMC, Palo Alto  
650-493-5000, ext. 65046

VARO, Rancho Cordova  
916-364-6791

VAMC, San Diego  
858-552-7519

VARO, San Diego  
619-400-5320

## Veterans Career Program

San Diego  
202-733-8807  
(covering AK, AZ, CA, HI, ID, NV, OR, WA)

## COLORADO (Wyoming)

VARO, Denver  
303-914-5590

## DELAWARE

VARO, Wilmington  
302-993-7252

## DISTRICT OF COLUMBIA

**PVA National Office**  
202-872-1300

## FLORIDA

VAMC, Lake City  
386-755-3016, ext. 2236

VAMC, Miami  
305-575-7180

VAMC, Orlando  
407-631-1000, ext. 11835

VARO, St. Petersburg  
727-319-7470

VAMC, Tampa  
813-978-5841

## GEORGIA

VARO, Atlanta  
404-929-5333

VAMC, Augusta  
706-823-2219

## Veterans Career Program

Atlanta  
202-710-6437  
202-304-8544  
(covering AL, AR, FL, GA, LA, MS, NC, PR, SC)

## ILLINOIS

VARO, Chicago  
312-980-4278

VAMC, Hines  
708-202-5623

## INDIANA

VARO, Indianapolis  
317-916-3626

## IOWA

VARO, Des Moines  
515-323-7544

## KANSAS

Wichita  
316-688-6875

## KENTUCKY

VARO, Louisville  
502-566-4430 / 4431

## LOUISIANA

VARO, New Orleans  
504-619-4380

## MAINE (Vermont, New Hampshire)

VAMROC, Augusta  
866-795-1911 / 207-621-7394

## MARYLAND

VARO, Baltimore  
410-230-4470, ext. 1020

## MASSACHUSETTS (Connecticut, Rhode Island)

VARO, Boston  
617-303-1395

VAMC, Brockton  
774-826-2219

## Veterans Career Program

Boston  
202-257-0144  
(covering CT, DE, MA, ME, NH, NJ, NY, PA, RI, VT)

## MICHIGAN

VARO, Detroit  
313-471-3996

## MINNESOTA

VAMC, Minneapolis  
612-629-7022

VARO, St. Paul  
612-970-5668

## Veterans Career Program

Minneapolis  
202-374-1989  
(covering IA, IL, MI, MN, ND, NE, SD, MT, WI, WY)

## MISSISSIPPI (Louisiana)

VARO, Jackson  
601-364-7188

## MISSOURI

VAMC, Kansas City  
816-922-2882

VAMC, St. Louis  
866-328-2670 / 314-894-6467

VARO, St. Louis  
314-253-4480

## NEBRASKA

VARO, Lincoln  
402-420-4017

## NEVADA (Utah)

VARO, Las Vegas  
702-791-9000, ext. 14458

VAMC, Reno  
775-321-4789

## NEW JERSEY

VARO, Newark  
973-297-3228

## NEW MEXICO

VAMC, Albuquerque  
505-265-1711, ext. 5046

VARO, Albuquerque  
505-346-4896

## NEW YORK

VAMC, Bronx  
866-297-1319  
718-584-9000, ext. 6272

VARO, Buffalo  
716-857-3353

VARO, New York  
212-807-3114

VAMC, Syracuse  
315-425-4400, ext. 53317

## NORTH CAROLINA

VARO, Winston-Salem  
336-251-0836

## OHIO

VAMC, Cleveland  
216-791-3800, ext. 4159

VARO, Cleveland  
216-522-3214

## OKLAHOMA (Arkansas)

VARO, Muskogee  
918-781-7768

VAMC, Oklahoma City  
405-456-5483

## OREGON (Idaho)

VARO, Portland  
503-412-4762

## PENNSYLVANIA

VARO, Philadelphia  
215-381-3057

VARO, Pittsburgh  
412-395-6255

## PUERTO RICO

VACHS, San Juan  
787-641-7582 ext. 11566

VARO, San Juan  
888-795-6550 / 787-772-7384

## SOUTH CAROLINA

VARO, Columbia  
803-647-2432

## SOUTH DAKOTA (North Dakota)

VAMROC, Sioux Falls  
605-333-6801

## TENNESSEE

VAMC, Memphis  
901-523-8990, ext. 7795

VARO, Nashville  
615-695-6383

## TEXAS

VAMC, Dallas  
214-857-0105

VAMC, Houston  
713-794-7993

VARO, Houston  
713-383-2727

VAMC, San Antonio  
210-617-5300, ext. 16819

VARO, Waco  
254-299-9944

## Veterans Career Program

San Antonio  
202-714-4777  
(covering CO, KS, NM, MO, OK, TX, UT)

## VIRGINIA

VAMC, Hampton  
757-722-9961, ext. 2943

VAMC, Richmond  
804-675-5316

VARO, Roanoke  
540-597-1707

## Veterans Career Program

Richmond  
202-769-7387  
(covering DC, IN, KY, MD, OH, TN, VA, WV)

## WASHINGTON (Alaska, Montana)

VAMC, Seattle  
206-768-5415

VARO, Seattle  
206-220-6149

## WEST VIRGINIA

VARO, Huntington  
304-399-9393

## WISCONSIN

VARO, Milwaukee  
414-902-5655



Being a mom with SCI/D comes with unique challenges and rewards.

### When DeAnna Sodoma was

21, a bike ride changed her life. The afternoon sun had reached that perilous point on the horizon where it blinded a motorist who was pulling into the driveway that Sodoma was riding across.

They collided. Sodoma got up. Urgent care didn't raise any red flags. So, she went on with her life, in pain, but walking. Ten months later, her legs went numb, and she's been paralyzed at level T9/T10 ever since.

"I was young. My life was going every which way," Sodoma says. "When all this happened, the doctor sat on my bed and said, 'You'll never walk again, but I want you to go on with your life, get married and have children.' Those words stuck with me."

Despite not knowing at that moment in that hospital bed if marriage or children would be part of her story, she took the doctor's words to heart and went on living a life of adventure that eventually did include marriage and three kids.

"I was so hungry to still live life. I didn't want to give up on being a mother," she says.

by Lisa Van Loo





# BIRTHDAY PARENTS

ILLUSTRATION BY KERRY RANDOLPH  
3D FONT DESIGNED BY FREEPIK



DeAnna Sodoma, right, had three sons, left, who now range in age from 20 to 27, after sustaining a level T9/T10 spinal cord injury when she was 21 years old.

COURTESY OF DEANNA SODOMA





## Mama Bear

Sodoma is one of an estimated 45,000 women in the U.S. living with a spinal cord injury or disease (SCI/D).

Statistics released by the National Institutes of Health reveal that the incidence and prevalence of SCI/D is growing among women. And while women living with SCI/D may face some physical challenges as they relate to sexual desire and response, childbearing and fertility are typically not impacted.

The challenge when it comes to pregnancy and motherhood, according to the National Institutes of Health, is finding the appropriate care due to accessibility or a lack of specialists in their geographic area.

**"Every day is a learning curve for us still. I was able to walk in the house until, like, 2022. My legs stopped after that. The reality is you have to make it work. My kids still need me to be there for them." — Monica Riggs**

Sodoma, who was paralyzed more than a decade before becoming pregnant with her first child, experienced some complications during delivery, but she went on to deliver two more healthy babies. She says her biggest concern was her ability to push when the time came.

But she wasn't alone when that time came, either.

She had people there to help hold her legs. She had straps to grab and gain leverage. And the foot stirrups women are all too familiar with were also helpful in that final stretch of labor.

"You feel like a super woman for sure, Wonder Woman," Sodoma says. "And then you become a mama bear."

Once she was home, raising those babies while her then-husband worked as a firefighter — meaning several days on before several days off — she just had to figure things out. She

didn't use a changing table, preferring to use a bed or couch that was level to her seated position. She found a way to use a blanket to lift a kid off the ground and into her lap.

And when she and the kids were in a store together, they had to stay close. She kept a visual on them at all times, knowing she couldn't run after them if they wandered away.

Now, Sodoma's boys range in age from 20 to 27, and her youngest is enlisted in the Marine Corps. The San Diego resident looks at her kids with pride and at her injury with some gratitude, knowing it inspired some of her most incredible adventures, from skydiving to hand-cycling to scuba diving.

She just followed her instincts, in life and as a mom.

"We live in an able-bodied world. You learn. It really is sink or swim. You have to try. You have no choice. And I swam, boy," Sodoma says. "It's all a learning process, whether you're disabled or not."

## Every Day Is A Learning Curve

Paralyzed Veterans of America (PVA) member-at-large Monica Riggs is navigating that learning process right now, while also figuring out how to live with a chronic, debilitating disease. It's connected to her service as chief pilot for the Air Force Reserve 18th Air Refueling Squadron based out of Wichita, Kan.

While flying missions in the Middle East, she was exposed to toxic chemicals. Her condition, known as neurosarcoidosis, is linked to that exposure, affecting her mobility in a way that is similar to multiple sclerosis (MS). She first noticed symptoms while lifting weights in 2019.

Instead of adding to the weight, she was gradually feeling like she needed to lift lighter weights.

"We [Riggs and her husband, Tim] blew it off to start with," she says. "I was in the best shape of my life and everything was going great."

But then one day, it felt like her fingers were asleep and wouldn't wake up. She finally made an appointment with a doctor once her left hand stopped responding. As a left-handed person, that was significant.



# MOM



COURTESY OF MONICA RIGGS

mobile and traveled quite a bit, spending nights away from home regularly.

Now, she uses a wheelchair all the time and is rarely away from home.

“They were very much used to Mom being on the road and being gone. Me not being home at night was not a huge deal to them,” Riggs says. “Every once in a while, I say, ‘This really stinks.’ The little things I took for granted, even going to school to get them.”

Riggs now has a caretaker during the day. She has an accessible van so she can transport the girls, ages 9 to 14, to wherever they need to go, and she and her husband are about to break ground on a new home in Wichita — one that is built for accessibility.

In their current home, Riggs stays on the main level. Her oldest daughter’s bedroom is on the lower level, so she isn’t able to go in there anymore. When her husband is gone on an overnight shift, her oldest daughter sleeps upstairs. That way, she’s able to help her mom, and the two have conversations they might not have otherwise.

“Every day is a learning curve for us still. I was able to walk in the house until, like, 2022. My legs stopped after that,” Riggs says. “The reality is you have to make it work. My kids still need me to be there for them. Nothing is going to be a perfect fit. And that’s OK. How you adapt to it and use it is going to make all the difference.”

**Monica Riggs, seated center, has learned how to do things differently as a mom with a disability.**

The condition progressed as she went through the process of finding a diagnosis, and at the time, her three girls were ages 8 and under. About 18 months after receiving a diagnosis and learning through the Department of Veterans Affairs (VA) that the condition was service-connected, she received medication that slows or stops the disease’s progression.

Motherhood for her now looks different from the way it did before. She used to be







## A Driving Force

PVA California Chapter member and Hacienda Heights, Calif., resident Sarah LaBrada likes to refer to her motherhood journey while living with multiple sclerosis (MS) as “entertainment in a handbasket.” Humor is a constant companion for the former combat medic who learned of her condition while enlisted with the Army nearly two decades ago.

After receiving her diagnosis, a doctor advised her that the longer she waited to start a family, the harder it might be as the disease progressed. She heeded the advice, and within 30 days, she was pregnant with her first son. After giving birth, she experienced a pretty profound flareup, which rendered her arms useless for a period of time.

Her second child was born about five years later. And when he was, she used a wheelchair for the next 368 days.

“But I persevered, and I learned to walk again,” LaBrada says. “When I say the VA helps people walk again, I’m a firm believer in that. They taught me to walk again.”

She walked with the help of bionic clothing, becoming the first veteran to utilize the CIONIC Neural Sleeve. The leg sleeves deliver electrical stimulation to help an individual walk. When she isn’t wearing the sleeves, LaBrada says walking is mentally taxing. She needs to think about every motion.

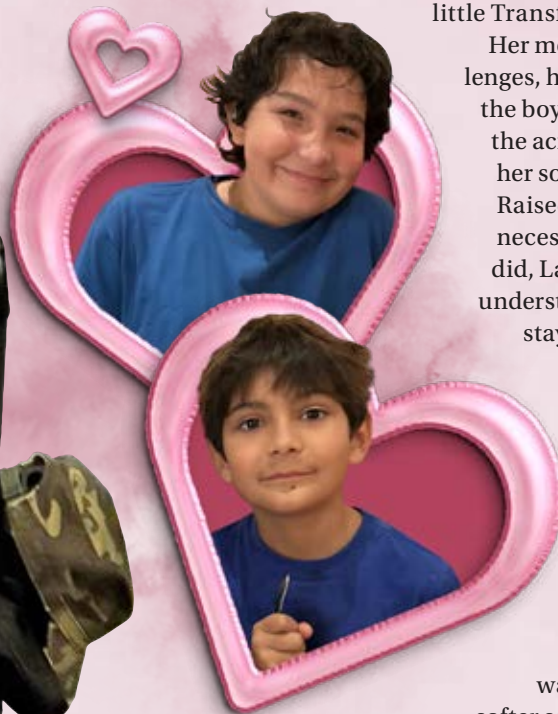
“It connects my brain to my legs,” she says of the wearable technology. “It’s nice to know I can get up and play with my kids if I want to. My kids call me Optimus Mommy. I’m a little Transformer.”

Her mobility has had its challenges, however, especially when the boys were younger. She uses the acronym BRAT to describe her sons, which stands for Born, Raised And Trained. Out of necessity, much like Sodoma did, LaBrada made sure her kids understood that they needed to stay close to her in public places because her limited mobility restricted the speed with which she could respond.

Motherhood, though, anchors her. LaBrada, who sported six-pack abs in her active Army days, is proud to have traded her washboard midsection for a softer souvenir from her pregnancies. She calls it her “badge of honor.”

And her boys, ages 8 and 13, keep her going, even when things get tough.

“Motherhood is my driving force,” LaBrada says. “They’re my world. I love my babies.” ■



Sarah LaBrada, left, says her sons, right, keep her going when things get tough.

COURTESY OF SARAH LABRADA



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SCAN HERE

## Kiley Book Out

### National Wheelchair

Basketball Association (NWBA) Hall of Famer and NWBA Hall of Fame chair Dave Kiley has published a

new book. *Wheel Head: The Wheel Print of David Kiley* focuses on Kiley's life story and the arc of adaptive sports over six decades. It is authored by Miles Thompson. It's available to order

"Those wanting to watch me crumble before their eyes ... are met with resilience, grit and a personal stamina that gives no quarter."

— Dave Kiley

through [amazon.com](https://amazon.com), [barnesandnoble.com](https://barnesandnoble.com) or [davekileydk3.com/wheel-head](https://davekileydk3.com/wheel-head).

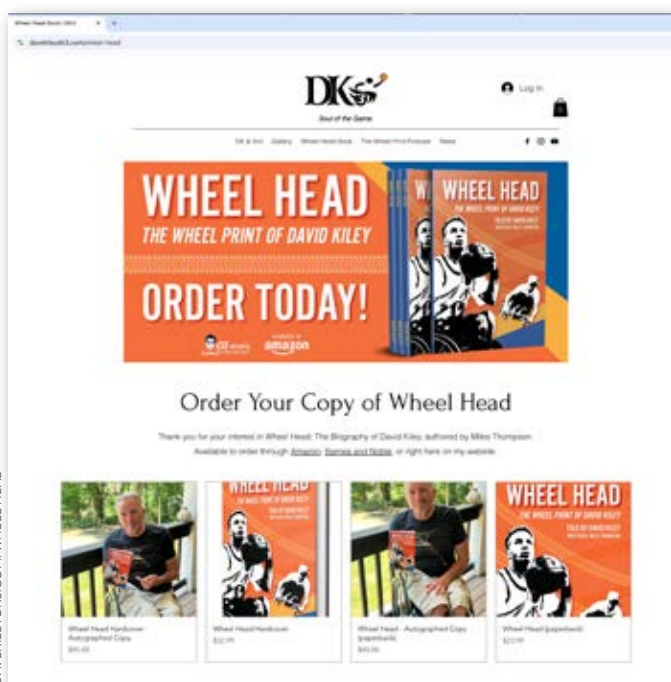
## Low-Point Rugby Team

Ten athletes have been named to this year's United States Wheelchair Rugby Association (USWRA) Low-Point Wheelchair

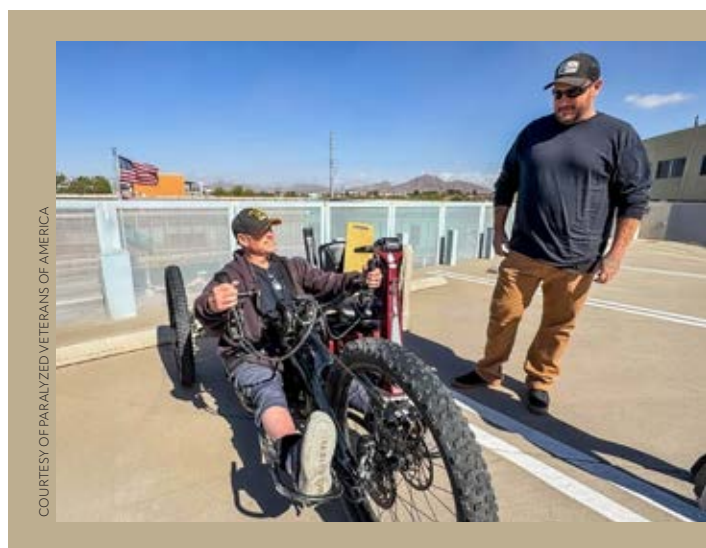


Rugby Team. They are: Sebastian Broussard (Ability360 Heat), Mike DeYoung (Las Vegas High Rollers), Mandy Marchiano (Maryland Mayhem), Joe Snyder (Brooks Bandits), Daniel Ortiz (TIRR Texans), Brian Sperle (TIRR Texans), Nate Washington (MedStar NRH United), Ryan Engelby (WASA/CKRI Lightning), Paul Hopkins (TIRR Texans) and Colton Parker (Denver Barbarians).

Selected on March 11, they will now begin preparing for an Oct. 16-18 tournament in Nottwil, Switzerland. ■



DAVEKILEYDK3.COM/WHEEL-HEAD



COURTESY OF PARALYZED VETERANS OF AMERICA

## Desert Cycling Clinic

Paralyzed Veterans of America (PVA) teamed up with the Phoenix Department of Veterans Affairs (VA) Health Care System for a two-day Intro To Paracycling veterans' clinic on March 11-12 in Phoenix. The clinic, which is offered at no cost to veterans, was designed for participants new to paracycling or who are looking to enhance their recreational riding and competitive racing skills. It provides essential knowledge and techniques to enjoy cycling in a rider's community and beyond. There will be another two-day paracycling veterans' clinic May 8-9 at the VA Salt Lake City Health Care System in Utah.



## Wheelchair 9-Ball Titles



PHOTO THIS PAGE BY SHAWN INTERRANTE

Mark Jones, right, won the Main Event title over Charles Interrante, left, at the Paralyzed Veterans of America ninth annual Charles "Chuck" Willis Memorial Wheelchair 9-Ball Championship March 14-15 at Diamond Billiards in Midlothian, Va.

Daniel Henson, left, took the Second Flight title over runner-up Johnny Holland, right, at the Paralyzed Veterans of America ninth annual Charles "Chuck" Willis Memorial Wheelchair 9-Ball Championship March 14-15 at Diamond Billiards in Midlothian, Va.



## Robotic Arm Testing

**For about a decade,** researchers in the Personal Robotics Lab at the University of Washington (UW) have been working to build a robot that can help feed people who can't eat on their own.

Researchers' first breakthrough, when the lab was at Carnegie Mellon University in Pittsburgh, was creating a robotic arm that could use a fork to feed someone a marshmallow. Since then, the robot graduated from feeding users fruit salads to full meals composed of nearly anything that can be picked up with a fork. Researchers also investigated how the robot can enhance the social aspects of dining.

Until recently, this work had mostly been evaluated in the lab. But last year, researchers deployed the assistive feeding arm in a pair of studies outside the lab. In the first study, six users with motor impairments used the robot to feed themselves a meal in a UW cafeteria, an office or a conference room. In the second study, one user, Jonathan Ko, who has a level C2 spinal cord injury and is a community researcher and co-author of the research, used the system at home for five days, having it feed him 10 meals.

"Our past studies have been in the lab because, if



The Assistive Dexterous Arm is controlled through an app to help people feed themselves.

you want to evaluate specific system components in isolation, you need to control all other aspects of the meal," says lead author Amal Nana-vati, a UW doctoral student in the Paul G. Allen School of Computer Science & Engineering, in a March UW release. "But that doesn't capture the diverse meal contexts that exist outside the lab. At the end of the day, the goal is to enable people to feed themselves in real environments, so we should also evaluate the system in those environments."

The system, which researchers dubbed Assistive Dexterous Arm, or ADA, consists of a robotic arm that can be affixed to something nearby, such as a power wheelchair or hospital table. The user specifies what bite he or she wants through an app (Ko used a

mouth-controlled mouse to initiate clicks), and the system then feeds the user that bite autonomously (though users can stop the arm with a "kill button"). The arm has a force sensor and camera to distinguish between foods and to get the food to the user's mouth.

In both studies, users successfully fed themselves their meals. In the first study, the robot acquired entrees with around 80% accuracy, which users in another study found to be the threshold for success. In the second study, the home's varied circumstances and environments — Ko could be eating while watching TV in low light or while working in bed — hindered the system's default functionality. But researchers designed the system to be customizable,

so Ko could control the robot and still feed himself all meals.

The team plans to continue improving the system for effectiveness and customizability.

"It was a really important step to take the robot out of the lab," Ko says. "You eat in different environments, and there are little variables that you don't think about. If the robot is too heavy, it might tilt a table. Or if the lighting isn't good, the facial recognition could struggle. But lighting is something you really don't think about when you're eating."

To see a video of the robotic arm, visit [youtube.com/watch?v=U10KC6tZc4o&t=112s](https://youtube.com/watch?v=U10KC6tZc4o&t=112s).

### Contributor:

Stefan Milne/University of Washington News



## Reducing MS Disparities

### A simple treatment

algorithm may help reduce treatment disparities for Hispanic and Black people with multiple sclerosis (MS), according to a preliminary study released March 3 that was presented at the American Academy of Neurology (AAN) 77th Annual Meeting April 5–9 in San Diego and online.

“Studies show Hispanic and Black people have higher levels of disability than white people but are not given prescriptions for the newer, more effective treatments as often as white people are,” says study author Annette Langer-Gould, MD, PhD, of Kaiser Permanente Southern California in Los Angeles and a member of AAN, in a March AAN release. “We’re excited that we’ve found a straightforward way to rapidly increase the use of these medications among all three groups, greatly improving their health.”

The program uses an algorithm to

determine the best disease-modifying treatments for people with MS. The algorithm uses readily available clinical factors such as weakness and bladder dysfunction, and also considers social factors such as out-of-pocket costs, transportation barriers, child-care and work schedules, but not race and ethnicity.

The intervention can match people to newer treatments that are highly effective at reducing MS relapses, including medications like natalizumab, rituximab and ofatumumab. Relapses are when MS symptoms like numbness, weakness, stiffness or vision problems appear for at least 24 hours. Because some of these drugs are expensive, not everyone with MS may be able to use them, which can widen health disparities.

The study involved 1,741 Hispanic people, 978 Black people and 3,400 white people with MS who were being treated with disease-modifying therapies.

Three years before the start of the study, Hispanic people had a higher annual relapse rate than white people, with 245 relapses compared to 156 relapses per 1,000 person-years. Person-years represent both the number of people in the study and the amount of time each person spends in the study. Black people had a higher relapse rate than white people during one year of the study.

Over the 12-year study, researchers found all three groups had an increased use of highly effective therapies, primarily rituximab, which is less expensive and can be given once a year or less. For Hispanic people, there was an 89% increase in use of highly effective therapies, for Black people an 87% increase, and for white people, 83%.

After adjusting for age and sex, researchers reported a decline in the annual relapse rate for each group.

The decline was greatest among Hispanic people at 90% fewer relapses per year, white people at 86%, and

Black people at 82%. By the end of the study, there was no longer a significant difference in the annual relapse

rate among Hispanic, Black and white people.

“It is encouraging that our program led to more effective treatments for people with MS resulting in a large reduction in relapse rates among Hispanic, Black and white people,” says Langer-Gould. “We show that using an algorithmic approach to increase the use of highly effective medications, particularly an affordable one like rituximab, can reduce racial and ethnic disparities in MS and greatly improve outcomes for all people with relapsing forms of MS.”

A study limitation was that it did not assess long-term disability or whether starting highly effective treatments at diagnosis is more beneficial than delaying these treatments until later in the disease course.

To read the original release, visit [aan.com/pressroom/home/press-release/5240](https://aan.com/pressroom/home/press-release/5240).

## Health Care Experiences

### People with disabilities

have more difficulty accessing health care and more negative interactions with health care providers than people without disabilities, according to a Rutgers Health study.

The study, published by researchers from the Rutgers Institute for Health, Health Care Policy and



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Aging Research and the Rutgers School of Public Health in New Jersey, in March examined satisfaction ratings, timeliness of care and patient-provider interactions among U.S. adults to assess the differences in health care experiences for those with and without disabilities.

According to previous research, one in four people in the U.S. has a disability. Those with disabilities experience significant health disparities, and structural inequities in health systems present barriers to accessing quality health care for people with disabilities.

Using data from a nationally representative survey, researchers examined the reported experiences of health care services by patients with varying disability statuses. According to the study, people with disabilities rated the health care services they received lower than the general population. For example, patients with disabilities were less likely to report that providers listened carefully, spent enough time with them, gave advice that was easy to understand or showed them respect.

“Our findings highlight the need for disability-competent and affirming health care, especially at a time when policies and initiatives impacting disabled patients are coming under attack,” says Elizabeth Stone, a faculty member in the Center for Health Services Research at Rutgers Institute for Health, Health Care Policy and Aging Research and lead author of the study, in a March Rutgers Institute for Health, Health Care Policy and Aging Research release.

One such policy is Section 504 of The Reha-



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bilitation Act of 1973, which prohibits discrimination on the basis of disability by any federally funded program and was updated in July 2024 to strengthen protections for people with disabilities in health care settings. In fall 2024, 17 states filed a lawsuit calling for the end of Section 504.

Researchers also found that people with multiple disabilities had the lowest satisfaction levels, and people with physical, cognitive and multiple disabilities had significantly worse experiences with health care services than those with sensory disabilities.

“Addressing disparities in the quality of health care for patients with disabilities requires unique approaches dependent on people’s specific needs,” says Stone, who is also an instructor of psychiatry at Rutgers Robert Wood Johnson Medical School. “But ultimately, interventions at the structural level are needed to address these concerning disparities in patient experiences.”

## Sleep Health & Mobility

**Poor sleep health can** lead to many daily problems, and for people with chronic illnesses, one of those problems can be difficulty with daily movement.

Researchers from University of Michigan Health used data from the Nurse’s

Health Study — a cohort study of more than 70,000 women nurses followed over time with surveys given every two years — and the dataset to focus on the impact of sleep on future mobility, with a special focus on chronic health conditions that are known to affect mobility.

The study findings, published in *Sleep Epidemiology* last December, suggested that poor sleep health predicted a decline in mobility over the eight years following a chronic health diagnosis.

Women with diabetes, osteoarthritis or multiple sclerosis (MS) who also had signs or symptoms of obstructive sleep apnea were more particularly likely to have future problems with mobility compared to counterparts who didn’t have signs of sleep apnea.

“Poor sleep is often overlooked or assumed to be a consequence of aging, functional decline or disability in those with chronic health conditions,” says senior author Tiffany J. Braley, MD, associate professor of neurology and director of the MS and neuroimmunology division at the University of Michigan Health, in a March Michigan Medicine release. “However, sleep disturbances and disorders may also be an upstream contributor to these issues.”

The study found that signs of obstructive sleep

apnea, reported sleep durations outside of the recommended guidelines and a perception of inadequate sleep were all associated with an increase in the future use of assistive devices to help with mobility, such as a cane or wheelchair.

“Identifying sleep disturbances or signs of a sleep disorder, providing information about healthy sleep habits and referral to a specialist when needed may help to reduce the progression of mobility issues,” says first author Daniel Whibley, PhD, assistant professor of physical medicine and rehabilitation at University of Michigan Health. “Our study is the first to observe this association in women, including those with and without long-term conditions, making this research important to consider when addressing ways to better the long-term health of women with these conditions.”

For patients, Whibley recommends speaking up about problems with sleep.

“Consider sleep as an important part of overall

health, especially for those who want to take a proactive role in addressing treatable causes of disability, as it can help patients take control of their physical health,” Whibley says.

To read the original release, visit [michiganmedicine.org/health-lab/sleep-health-may-impact-mobility-women-chronic-conditions](https://michiganmedicine.org/health-lab/sleep-health-may-impact-mobility-women-chronic-conditions).

**Contributor:**  
Valerie Goodwin



## Cell-Catching Implant For MS

**A sponge-like implant** in mice helped guide a treatment that slowed or stopped a degenerative condition similar to multiple sclerosis (MS) in humans. It also gave University of Michigan (UM) researchers a first look at how primary progressive MS, the fastest-progressing version of the disease, attacks the central nervous system early on.

If administered early, the nanoparticle-based treatment prevented mice

from developing symptoms such as paralysis. If given after the first symptoms emerged, it reduced symptom scores by half compared to untreated mice.

On average, primary progressive MS causes severe disability within 13 years — including balance issues, difficulty walking and vision problems — but this can also happen within two years.

“Right now, we simply can’t get access to diseased tissue from MS patients in any regular way. Some patients donate brains after

death, but at that point the disease has progressed quite far,” says Aaron Morris, UM assistant professor of biomedical engineering and co-corresponding author of the study in the *Proceedings of the National Academy of Sciences*, in a February UM release.

Without an understanding of how the disease works, researchers have been unable to develop effective treatments. Currently, the only Food and Drug Administration-approved drug helps slow disease progression but does not offer full

remission. Since it works by damping down the immune system, it also exposes patients to infection.

To enable better treatments, the research team used a sponge-like implant, previously used to diagnose relapsing MS or discover whether an implanted organ is being rejected. Also known as a scaffold, it is a cylinder of biodegradable polyester, 13 millimeters diameter and 2 millimeters in height, full of small pores where cells can attach.

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around the shoulder blades, the team induced the MS-like autoimmune condition in half of the mice, while the other half served as a healthy comparison. Over several weeks, immune cells attracted to the foreign object grew into the pores, along with other cells. This created an easily biopsied tissue surrogate outside of the central nervous system that provides clues to the disordered immune response in MS.

The team analyzed the tissue from the sponges with single-cell

RNA sequencing to discover what individual cells were doing, which helped unravel differences between diseased and healthy tissue. A group of proteins called CC chemokines were particularly overactive in diseased tissue. These proteins call over other cells to fight infection, but when the call is too loud, they trigger the immune cells to attack healthy tissue.

With this information in hand, the researchers developed injectable nanoparticles, just 400

nanometers in diameter, that surround a key CC chemokine and disrupt the misplaced inflammation. This mechanism prevented symptoms from developing when the mice were treated early and reduced their symptoms by more than half if given after onset. A close look at immune cells confirmed less disease activity in nanoparticle-treated mice.

“The scaffold provides an unprecedented ability to track disease dynamics and to investigate the underlying mechanisms,

particularly at early stages. Therapies targeting these early mechanisms can halt disease progression before significant tissue damage,” says Lonnie Shea, the Steven A. Goldstein Collegiate Professor of Biomedical Engineering and co-corresponding author of the study.

#### Contributor:

Patsy DeLacey ■



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# EVENT

## February 2025

|   |                           |                |
|---|---------------------------|----------------|
| Bayou Gulf States Bocchia 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 Gulf Coast Bowling Tournament           | February 19-21, 2025      | Tampa, FL      |
| USA Bocchia Regional Tournament - hosted by PVA | February 28-March 3, 2025 | Dade City, FL  |

## March 2025

|   |                   |                      |
|---|-------------------|----------------------|
| Intro to Paracycling Camp - Stop 1              | March 6-7, 2025   | Phoenix, AZ          |
| Tampa Pickleball Clinic                         | March 7, 2025     | Tampa, FL            |
| USA Bocchia Regional Tournament - hosted by PVA | March 7-9, 2025   | San Antonio, TX      |
| Mid-Atlantic Billiards Tournament               | March 14-16, 2025 | Midlothian, VA       |
| PVA Wheelchair Basketball Camp & Invitational   | March 19-23, 2025 | Colorado Springs, CO |
| Wisconsin Air Gun Tournament                    | March 21-22, 2025 | Racine, WI           |
| Bayou Brawl Bass Tournament                     | March 28-30, 2025 | Westwego, LA         |
| Wheelchair Football Camp                        | March 28-30, 2025 | Tampa, FL            |

## April 2025

|  |                   |                   |
|--|-------------------|-------------------|
| Citrus Slam Bass Fishing Tournament                | April 4-6, 2025   | Kissimmee, FL     |
| USA Bocchia Regional Tournament - hosted by PVA    | TBD               | San Diego, CA     |
| Pocahontas Off-Road Spring Camp & 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       |



# SCHEDULE 2025

## April 2025 | Continued

|                                  |                      |                    |
|----------------------------------|----------------------|--------------------|
| 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    |
| Intro to Paracycling Camp - Stop 3             | May 21-22, 2025     | Milwaukee, WI      |
| Vaughan Trapshoot Tournament                   | May 23-25, 2025     | Elburn, IL         |
| Texas Air Gun Tournament                       | May 31-June 1, 2025 | San Antonio, TX    |

## June 2025

|  |                  |                  |
|--|------------------|------------------|
| Wheelchair Basketball Camp                       | June 6-8, 2025   | Arlington, TX    |
| Capital Clash Bass Tournament (Year-end event)   | June 13-15, 2025 | La Plata, MD     |
| 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 |
| PVA Bowling National Championship - Great Plains | June 27-29, 2025 | Omaha, NE        |

## July 2025

|                                    |                  |                 |
|------------------------------------|------------------|-----------------|
| National Veterans Wheelchair Games | July 17-22, 2025 | Minneapolis, MN |
|------------------------------------|------------------|-----------------|



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# andfinally...

## An Advocate Is Paramount

I recently went to the emergency room (ER) located in the Department of Veterans Affairs (VA) hospital where I've been receiving care for more than three decades.

This was the third time in just a year that kidney stones had triggered a serious infection, and as I lay on a gurney, I wondered how much more my 60-year-old body could take. But it wasn't just my physicality that was under duress, so was my mental state.

While my body did battle with MRSA and sepsis, my mental game was engaged in a full-court press. Sure, the docs were calling most of the shots, but I needed to be vigilant in my advocacy. After all, my most dependable advocate was picking up the kids at school, and I was headed to the operating room.

During the pre-op huddle, the team discussed the basic stuff like my vital signs and which kidney was causing the problems. And, like previous pre-op huddles, there was a focus on some of the nuances relating to my tetraplegia, such as my predisposition for autonomic dysreflexia in addition to my allergies relating to specific antibiotics such as vancomycin.

My understanding was that we covered all the important stuff and we were ready to proceed. But once we were in the operating room, clinicians were still addressing some important issues, such as how much anesthesia and which antibiotics were to be used.

Calculation of a patient's body mass index (BMI) is a significant factor when determining the appropriate dosage of anesthesia. However, someone in the ER recorded my height as 6 inches rather than 6 feet, so when my BMI was calculated to be 3,906 rather than 26, the nurse and I shared a nervous laugh while she corrected the mistake.

When someone in the operating room asked about which antibiotic was to be used, someone responded, "vancomycin." I quickly said, "No, I already told you that I go into autonomic dysreflexia when given vancomycin!" I don't recall much of the conversation that followed, but I woke up on daptomycin.

I was then transferred to the direct observation unit, where I was expecting another round of educating clinicians on all things relating to spinal cord injury (SCI). However, I got lucky this time; it turns out the nurse assigned to me had worked in the SCI center just a few years ago, so the learning curve was pretty flat.

Truth be told, I hate to see a nurse leave the SCI center, but it's comforting to know they continue their good work in other departments in the hospital where patients with SCI receive care. Furthermore, it's VA policy for nurses assigned to the SCI center to visit patients who are admitted elsewhere in the hospital.

However, it was only after I was admitted to the SCI center that the need for vigilance became less of a concern and I could begin to relax. After all, this center was built as a place for people like me to come home to, and that's exactly how I felt.

While it's comforting to be surrounded by clinicians who specialize in caring for veterans with SCI, there's still a need to ask questions and direct your care when appropriate.

For example, one of my roommates had been having a difficult time. He was probably overwhelmed with all the stuff that was happening, but when his wife arrived, she scolded him for not knowing everything that was going on with his case. She said in a very stern tone, "Why don't you ask questions?!" Now, I have to track down your doctors in the halls and ask them what's going on. They must think I'm a crazy bitch!" That's when my wife looked at me, raised her right eyebrow like Mr. Spock and whispered, "Now you know how I feel."

I'm very fortunate to be married to someone who takes better care of me than I do. Gone are the days when a fever was a mere

inconvenience. Nowadays, my wife wastes no time in driving me to the hospital when something doesn't feel right.

Even when I'm admitted as an inpatient,

been afraid to fight my battles. For a while, I thought I might be caught up in a chronic case of Munchausen

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to Be  
THE  
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When it comes to my care, she never accepts the status quo, always thinks in terms of "we" and has never been afraid to fight my battles.

## Caregiver's Note

PVA Publications Editor-In-Chief Al Kovach Jr., received this reader's response to his Reasons & Remarks column in the March issue of PN: "Thank you so much for this!! I've had the pleasure of taking care of Bobby Jackson (Paralyzed Veterans of America Gateway Chapter member) for 38 years. I'm not his wife, mother, family member. He has become our family! My family has lived with him the whole time ... I've had to advocate for him many times. Thanks for validation of caregivers and family to do everything they can to make sure their person comes home!! Sometimes I really do feel like a monster, as I put in writing on my cabinets at home."

— Lanna Brickhaus





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